

# Freedom to be altruistic: allowing for risk/knowledge ratios in decisions concerning multiple sclerosis research

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**Related article:** Laupacis A, Slutsky AS. Endovascular treatment for multiple sclerosis: The intersection of science, policy and the public. *Open Med* 2010;4(4):E197-E199. Drs. Laupacis and Slutsky declined *Open Medicine's* invitation to reply.

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In their thoughtful criticism of the conclusion by a joint panel of the Canadian Institutes of Health Research and the Multiple Sclerosis (MS) Society of Canada concerning Dr. Paolo Zamboni's "liberation procedure" for chronic cerebrospinal venous insufficiency (CCSVI), Dr. Andreas Laupacis and Dr. Arthur Slutsky missed an important public policy point: there is an additional, little-developed freedom involved in patient autonomy in Canadian law, which is the other face of the coin of informed consent. Note that I speak of a coin of freedom, not of right. If there is a right, someone is under a duty, and there is no duty on anyone to conduct studies of the liberation procedure. The court would reject a claim for an order against researchers or institutions that such a study be done. The correlative of a freedom—the classic example is the freedom to walk in a public park—is that no one has the right to object. The legal philosophers call this a "no-right" to distinguish it from a duty. In the case we are considering, no researcher has the legal right to omit obtaining informed consent when signing up subjects (indeed, this side of the coin is now treated as a duty of disclosure when the researcher is embarked on a study and is recruiting subjects); similarly, for the obverse of the freedom coin in question, for patients satisfying the requirements for enrolment in a study of the liberation procedure, no researcher has the right to refuse those who choose to participate, as argued below.

Laupacis and Slutsky summarized the panel's decision as follows: "the evidence linking CCSVI and MS was so unconvincing that it would be inappropriate at this time to perform a clinical trial examining the benefits and risks of endovascular treatment as a therapy for MS." Risk/benefit is an incomplete ratio: also relevant is risk/knowledge. Health Canada advises researchers developing informed consent documents not to mention that a research ethics committee has approved the research because "approval means only that the Committee considers the risks to fall within a scale of risks which a reasonable participant may be invited to accept, and that the risk-to-benefit (or *risk-to-knowledge*) ratio of the study appears favourable."<sup>1</sup> [*Emphasis added.*]

Where is the fair-minded risk-to-knowledge analysis in the panel's deliberations or its conclusion? A patient has a right to determine what shall be done to his or her body, as well as what shall not be done to it.

The freedom I claim is implied in an extract of the decision by Justice Sydney Robins in an Ontario Court of Appeal case, *Fleming v Reid*,<sup>2</sup> quoted in a publication of the Canadian Medical Protective Association.<sup>3</sup> There, Justice Robins said:

*The right to determine what shall, or shall not, be done with one's own body, and to be free from non-consensual medical treatment, is a right deeply rooted in our common law. This right underlines the doctrine of informed consent. With very limited exceptions, every person's body is considered inviolate, and, accordingly, every competent adult has the right to be free from unwanted medical treatment. The fact that serious risks or consequences may result from a refusal of medical treatment does not vitiate the right of medical self-determination. The doctrine of informed consent ensures the freedom of individuals to make choices about their medical care. It is the patient, not the physician, who ultimately must decide if treatment—any treatment—is to be administered. [*Emphasis added.*]*

The headnote to the *Fleming v Reid* case report<sup>2</sup> explains the issues and decision in the case and helps elucidate the freedom that I assert exists:

Criminal Law — Detention and release after trial — Custody of insane persons — Powers of Lieutenant Governor.

Compulsory treatment of involuntary patients — Patients, when competent, expressing wish not to receive treatment — Treatment offending Charter — Canadian Charter of Rights and Freedoms, ss. 1, 7 — Mental Health Act, R.S.O. 1980, c. 262, ss. 35(2)(b)(ii), 35a.

S. 35a and s. 35(2)(b)(ii) of the Act are inconsistent with s. 7 of the Charter to the extent that they empower the review board to authorize the psychiatric treatment of an involuntary incompetent patient contrary to the patient's competent refusal to accept such treatment as expressed

through the patient's substitute consent giver. These sections are not saved by s. 1 of the Charter. The sections deny the patient any hearing in which they may assert their competent wishes through their substitute. *The hearing provided by the sections turns on the question of the patient's best interests, not on why their competent wishes should not be honoured.* This is a violation of the principles of fundamental justice that cannot be demonstrably justified in a free and democratic society. [Emphasis added.]

If Canadians with MS are given full information about the risks of the procedure, the possibility of immediate benefit to the individual subject (which I grant is probably small, but is unquantifiable) and the likelihood of gains in knowledge that will benefit all patients with MS, one can confidently predict that enough Canadian patients will altruistically accept the opportunity to participate in a multi-centre study to rule in or rule out this treatment for MS.

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## REFERENCES

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